

Community Counts

The HTC Population Profile

The HTC Population Profile is a set of twelve data items collected on patients with bleeding disorders or venous thromboembolism. These patients receive care at hemophilia treatment centers (HTCs) that are part of the United States Hemophilia Treatment Center Network (USHTCN). The USHTCN is a network of 132 HTCs located throughout the US and its territories. The HTCs practice a model of care delivery called comprehensive care. This care includes specialized prevention, diagnostic, and treatment programs. It also includes family-centered education, research, and support services for patients and families living with bleeding disorders. Congress provides support to these centers through the Maternal and Child Health Bureau and the Centers for Disease Control and Prevention (CDC). USHTCN centers that participate in the Community Counts project collect the data. Community Counts is sponsored by CDC to monitor the complications of bleeding disorders.

The twelve items collected are:

1. Year of birth
2. Gender
3. Ethnicity
4. Race
5. Three-digit zip code of residence
6. Insurance status
7. Primary bleeding disorder diagnosis
8. Baseline factor activity
9. Von Willebrand factor activity (VWF:RCof)
10. Von Willebrand factor antigen level (VWF:Ag)
11. Hepatitis C (HCV) infection status
12. Human immunodeficiency virus (HIV) infection status.

The data are collected on a calendar-year basis. HTC report on patients that receive care either in person or by telemedicine during a given calendar year. Some HTCs report data throughout the year while others report data only at the end of the year. Most data are reported by February of the following year, but some records may be received later.

The HTCs began collecting data for the HTC Population Profile in 2012. One hundred twenty-two HTCs provided data for 2012. This includes four centers that provided data only for 2012. For 2013, 124 HTCs provided data. This includes six that did not provide data in 2012. As of September 30, 2014, 120 centers have provided data for 2014. This includes two that did not provide data in 2012 or 2013. As of September 30, 2014, 111 HTCs have provided data for all three years (2012, 2013 and 2014).

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HTC Population Profile Patient Characteristics by Calendar Year

Data reported from 1/1/2012 through 9/30/2014

		2012	2013	2014	Unique patients ¹	Multi-year patients ²
		#	#	#	#	#
	# of patients	24970	25399	15581	39353	18891
Age	<2	792	823	526	1225	254
	2--10	5613	5519	3367	7910	4309
	11--19	6944	7058	4460	10881	5638
	20--44	6869	6843	4271	11146	5255
	45--64	3475	3657	2099	5819	2445
	65+	1277	1499	858	2372	990
Gender†	Male	16650	16558	10351	24151	13496
	Female	8320	8841	5230	15202	5395
Ethnicity	Hispanic, Latino/a, or Spanish origin	3681	3645	2263	5475	2921
	Not Hispanic, Latino/a, or Spanish origin	21086	21512	13197	33587	15797
	Unknown	203	242	121	291	173
Race	American Indian/Alaska Native	173	159	103	254	127
	Asian	694	722	515	1050	603
	Black or African American	2858	2885	1821	4485	2167
	Native Hawaiian or other Pacific Islander	107	89	51	142	84
	White	20958	21218	12782	32839	15677
	More than one of these	82	141	93	203	107
	Unknown	98	185	216	380	126
Insurance status	Insured	23672	24342	15061	37662	18108
	Uninsured	913	862	450	1311	615
	Unknown	385	195	70	380	168
Diagnosis	Blood coagulation disorder without specific diagnosis	178	278	76	450	59
	Ehlers-Danlos syndrome	44	39	26	78	22
	Factor I, hereditary	56	73	35	106	41
	Factor II, hereditary	18	14	12	31	11
	Factor V, hereditary	96	105	71	198	57
	Factor VII, hereditary	454	452	249	775	307
	Factor VIII, hereditary	9303	8875	5806	11984	8158
	Factor IX, hereditary	2801	2688	1657	3688	2359
	Factor X, hereditary	68	55	40	93	51
	Factor XI, hereditary	267	238	162	454	160
	Factor XIII, hereditary	72	84	58	105	66
	Factors V & VIII, combined	*	*	*	10	*
	Alpha-2 antiplasmin deficiency	*	*	*	5	*
	Platelet function disorder	1481	1555	1073	2790	1011
	PAI-1 deficiency	106	80	29	146	50
	Thrombocytopenia, hereditary	132	110	44	209	54
	Venous thromboembolism (VTE)	3436	4535	2635	7845	2042
	Von Willebrand disease, type 1	5083	4851	2804	8226	3465
	Von Willebrand disease, type 1C	9	14	12	25	11
	Von Willebrand disease, type 2A	317	325	187	499	247
	Von Willebrand disease, type 2B	193	183	102	297	133
	Von Willebrand disease, type 2M	144	167	82	188	140
	Von Willebrand disease, type 2N	31	41	32	67	27
	Von Willebrand disease, type 2, type unknown	82	109	67	178	60
	Von Willebrand disease, type 3	225	218	135	275	191
	Von Willebrand disease, unknown	320	270	165	561	146
	Von Willebrand disease, type other	43	30	16	70	12
History of HCV infection	Yes	2985	2751	1787	3722	2607
	No	14668	13692	8191	20374	11163
	Unknown	3881	4421	2968	7412	3079
	Not Applicable‡	3436	4535	2635	7845	2042
History of HIV infection	Yes	924	832	547	1116	804
	No	16430	15245	9193	22470	12645
	Unknown	4180	4787	3206	7922	3400
	Not Applicable‡	3436	4535	2635	7845	2042

¹"Unique patients" is the total number of individual patients reported by the HTC's since January 2012. This includes individuals reported in only a single calendar year as well as those reported in more than one calendar year. If an individual was reported in more than one calendar year, they are counted only once in this column.

²"Multi-year patients" is the total number of individual patients who were reported by the HTC's in more than one calendar year since January 2012. Patients who have been reported in only a single calendar year are not included in this count.

†The HTC Population Profile contains twelve transsexual individuals. For confidentiality purposes, the number of transsexual patients is too small to report by year or other characteristics. Transsexual patients have been included in the counts of male and female according to the gender assigned to them at birth. This is because the most common congenital bleeding disorders, hemophilia and von Willebrand disease, tend to affect the sexes differently.

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‡HCV and HIV status are not recorded for VTE patients.

HTC Population Profile Patient Characteristics, Factor VIII and Factor IX

Data reported from 1/1/2012 through 9/30/2014

		Factor VIII (n=11984)				Factor IX (n=3688)			
		Mild	Moderate	Severe	Severity Unknown	Mild	Moderate	Severe	Severity Unknown
		# (%)	# (%)	# (%)	# (%)	# (%)	# (%)	# (%)	# (%)
# of patients		3977 (100)	1850 (100)	5989 (100)	168 (100)	1277 (100)	1305 (100)	1065 (100)	41 (100)
Age	<2	95 (2)	66 (4)	167 (3)	10 (6)	32 (3)	46 (4)	39 (4)	3 (7)
	2--10	770 (19)	410 (22)	1419 (24)	25 (15)	249 (19)	302 (23)	233 (22)	6 (15)
	11--19	992 (25)	443 (24)	1353 (23)	33 (20)	288 (23)	293 (22)	214 (20)	9 (22)
	20--44	1171 (29)	631 (34)	2338 (39)	69 (41)	389 (30)	394 (30)	394 (37)	17 (41)
	45--64	653 (16)	232 (13)	620 (10)	23 (14)	226 (18)	202 (15)	152 (14)	6 (15)
	65+	296 (7)	68 (4)	92 (2)	8 (5)	93 (7)	68 (5)	33 (3)	0 (0)
Gender†	Male	3402 (86)	1822 (98)	5958 (99)	119 (71)	1000 (78)	1297 (99)	**	31 (76)
	Female	575 (14)	28 (2)	31 (1)	49 (29)	277 (22)	8 (1)	**	10 (24)
Ethnicity	Hispanic, Latino/a, or Spanish origin	770 (19)	334 (18)	973 (16)	37 (22)	84 (7)	95 (7)	179 (17)	8 (20)
	Not Hispanic, Latino/a, or Spanish origin	3190 (80)	1512 (82)	5005 (84)	131 (78)	1157 (91)	1201 (92)	885 (83)	30 (73)
	Unknown	17 (0)	4 (0)	11 (0)	0 (0)	36 (3)	9 (1)	1 (0)	3 (7)
Race	American Indian/Alaska Native	64 (2)	13 (1)	53 (1)	3 (2)	*	14 (1)	7 (1)	1 (2)
	Asian	84 (2)	74 (4)	280 (5)	9 (5)	21 (2)	13 (1)	51 (5)	0 (0)
	Black or African American	242 (6)	276 (15)	939 (16)	20 (12)	124 (10)	60 (5)	168 (16)	2 (5)
	Native Hawaiian or other Pacific Islander	7 (0)	8 (0)	31 (1)	1 (1)	*	10 (1)	9 (1)	0 (0)
	White	3528 (89)	1449 (78)	4602 (77)	135 (80)	1105 (87)	1197 (92)	821 (77)	36 (88)
	More than one of these	20 (1)	9 (0)	40 (1)	0 (0)	*	*	*	0 (0)
	Unknown	32 (1)	21 (1)	44 (1)	0 (0)	20 (2)	*	*	2 (5)
Insurance status	Insured	3798 (95)	1778 (96)	5772 (96)	145 (86)	1089 (85)	1057 (81)	1025 (96)	32 (78)
	Uninsured	148 (4)	65 (4)	182 (3)	16 (10)	143 (11)	238 (18)	28 (3)	5 (12)
	Unknown	31 (1)	7 (0)	35 (1)	7 (4)	45 (4)	10 (1)	12 (1)	4 (10)
History of HCV infection	Yes	590 (15)	404 (22)	1662 (28)	16 (10)	143 (11)	245 (19)	364 (34)	4 (10)
	No	2736 (69)	1278 (69)	3738 (62)	89 (53)	868 (68)	861 (66)	606 (57)	20 (49)
	Unknown	651 (16)	168 (9)	589 (10)	63 (38)	266 (21)	199 (15)	95 (9)	17 (41)
History of HIV infection	Yes	95 (2)	118 (6)	707 (12)	9 (5)	12 (1)	31 (2)	97 (9)	0 (0)
	No	3157 (79)	1528 (83)	4583 (77)	96 (57)	978 (77)	1038 (80)	848 (80)	23 (56)
	Unknown	725 (18)	204 (11)	699 (12)	63 (38)	287 (22)	236 (18)	120 (11)	18 (44)

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HTC Population Profile Patient Characteristics, von Willebrand Disease (VWD)

Data reported from 1/1/2012 through 9/30/2014

		VWD (n=10386)							
		Type 1		Type 2		Type 3		Type other and Type unknown	
		#	(%)	#	(%)	#	(%)	#	(%)
	# of patients	8251	(100)	1229	(100)	275	(100)	631	(100)
Age	<2	75	(1)	23	(2)	6	(2)	6	(1)
	2--10	2029	(25)	313	(25)	53	(19)	162	(26)
	11--19	3430	(42)	326	(27)	56	(20)	219	(35)
	20--44	1863	(23)	310	(25)	96	(35)	139	(22)
	45--64	662	(8)	159	(13)	51	(19)	68	(11)
	65+	192	(2)	98	(8)	13	(5)	37	(6)
Gender†	Male	2951	(36)	543	(44)	140	(51)	217	(34)
	Female	5300	(64)	686	(56)	135	(49)	414	(66)
Ethnicity	Hispanic, Latino/a, or Spanish origin	1272	(15)	159	(13)	23	(8)	98	(16)
	Not Hispanic, Latino/a, or Spanish origin	6927	(84)	1025	(83)	252	(92)	523	(83)
	Unknown	52	(1)	45	(4)	0	(0)	10	(2)
Race	American Indian/Alaska Native	41	(0)	9	(1)	*		*	
	Asian	187	(2)	37	(3)	12	(4)	18	(3)
	Black or African American	594	(7)	108	(9)	19	(7)	52	(8)
	Native Hawaiian or other Pacific Islander	40	(0)	*		*		*	
	White	7268	(88)	1037	(84)	239	(87)	543	(86)
	More than one of these	49	(1)	*		*		*	
	Unknown	72	(1)	31	(3)	1	(0)	10	(2)
Insurance status	Insured	7988	(97)	1138	(93)	266	(97)	599	(95)
	Uninsured	177	(2)	52	(4)	7	(3)	17	(3)
	Unknown	86	(1)	39	(3)	2	(1)	15	(2)
History of HCV infection	Yes	70	(1)	59	(5)	61	(22)	5	(1)
	No	5789	(70)	846	(69)	176	(64)	431	(68)
	Unknown	2392	(29)	324	(26)	38	(14)	195	(31)

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Less than 0.5% of VWD patients have a history of HIV infection. About 70% are negative and about 30% have an unknown status.

HTC Population Profile Patient Characteristics, Rare Factor Deficiencies (excluding Factor VIII and Factor IX)

Data reported from 1/1/2012 through 9/30/2014

		FI		FII		FV		Factors V & VIII, combined		FVII		FX		FXI		FXIII		Alpha-2 Antiplasmin Deficiency		PAI-1 Deficiency	
		#	(%)	#	(%)	#	(%)	#	(%)	#	(%)	#	(%)	#	(%)	#	(%)	#	(%)	#	(%)
# of patients		106	(100)	31	(100)	198	(100)	10	(100)	775	(100)	93	(100)	454	(100)	105	(100)	5	(100)	146	(100)
Age	<2	*		*		*		*		16	(2)	*		16	(4)	*		*		*	
	2–10	32	(30)	10	(32)	32	(16)	*		253	(33)	20	(22)	77	(17)	20	(19)	*		45	(31)
	11–19	29	(27)	9	(29)	70	(35)	*		290	(37)	30	(32)	131	(29)	27	(26)	*		69	(47)
	20–44	28	(26)	9	(29)	68	(34)	*		153	(20)	24	(26)	111	(24)	40	(38)	*		17	(12)
	45–64	9	(8)	*		14	(7)	*		46	(6)	13	(14)	65	(14)	11	(10)	*		7	(5)
	65+	*		*		*		*		17	(2)	*		54	(12)	*		*		*	
Gender†	Male	44	(42)	15	(48)	81	(41)	*		380	(49)	38	(41)	221	(49)	61	(58)	*		57	(39)
	Female	62	(58)	16	(52)	117	(59)	*		395	(51)	55	(59)	233	(51)	44	(42)	*		89	(61)
Ethnicity	Hispanic, Latino/a, or Spanish origin	15	(14)	10	(32)	36	(18)	0	(0)	176	(23)	27	(29)	53	(12)	23	(22)	*		23	(16)
	Not Hispanic, Latino/a, or Spanish origin	89	(84)	21	(68)	159	(80)	10	(100)	595	(77)	66	(71)	398	(88)	82	(78)	*		120	(82)
	Unknown	2	(2)	0	(0)	3	(2)	0	(0)	4	(1)	0	(0)	3	(1)	0	(0)	0	(0)	3	(2)
Race	American Indian/Alaska Native	*		*		0	(0)	0	(0)	8	(1)	0	(0)	0	(0)	0	(0)	0	(0)	*	
	Asian	6	(6)	*		*		0	(0)	14	(2)	*		19	(4)	*		*		*	
	Black or African American	6	(6)	*		10	(5)	*		143	(18)	15	(16)	23	(5)	19	(18)	0	(0)	14	(10)
	Native Hawaiian or other Pacific Islander	0	(0)	0	(0)	0	(0)	0	(0)	*		0	(0)	0	(0)	0	(0)	0	(0)	*	
	White	90	(85)	24	(77)	181	(91)	7	(70)	592	(76)	70	(75)	408	(90)	79	(75)	*		124	(85)
	More than one of these	*		0	(0)	0	(0)	0	(0)	*		0	(0)	*		*		0	(0)	0	(0)
	Unknown	2	(2)	0	(0)	*		*		12	(2)	*		*		1	(1)	0	(0)	1	(1)
Insurance status	Insured	101	(95)	29	(94)	192	(97)	9	(90)	746	(96)	90	(97)	444	(98)	103	(98)	5	(100)	133	(91)
	Uninsured	*		*		*		*		18	(2)	*		5	(1)	*		0	(0)	*	
	Unknown	*		*		*		*		11	(1)	*		5	(1)	*		0	(0)	*	
History of HCV infection	Yes	8	(8)	5	(16)	*		*		11	(1)	6	(6)	17	(4)	8	(8)	*		*	
	No	60	(57)	21	(68)	*		*		514	(66)	65	(70)	317	(70)	72	(69)	*		*	
	Unknown	38	(36)	5	(16)	*		*		250	(32)	22	(24)	120	(26)	25	(24)	*		*	

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